



Health-related quality of life assessment in Serbian schoolchildren hospitalized for malignant disease

Kvalitet života dece školskog uzrasta u Srbiji hospitalizovane radi lečenja maligne bolesti

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Abstract

Background/Aim. Although long-term survival of childhood cancer patients is significantly improved, prolonged treatment and hospitalization might have negative impacts on child development. The aim of this study was to verify profile of health-related quality of life parameters in population of schoolchildren during hospitalization and treatment for malignant disease. **Methods.** The Serbian version of Pediatric Quality of Life Inventory Version 4.0 (PedsQL™4.0) Generic Core Scales was applied. A total of 120 schoolchildren were analyzed: 60 patients hospitalized for prolonged malignant disease treatment and 60 healthy schoolchildren from public schools. The study was done at the Institute for Oncology and Radiology of Serbia, as well as in four schools. **Results.** Generally, schoolchildren hospitalized for cancer treatment demonstrated lower scores on physical, emotional, social and school functioning when compared to healthy schoolchildren from regular public schools. Significant differences were observed for all the 8 items of the Physical Health Scale, in 2 out of 5 items of the Emotional Functioning Scale, in 4 out of 5 items of the Social Functioning Scale, and 3 out of 5 items of the School Functioning Scale. **Conclusions.** The Serbian version of PedsQL™ 4.0 Generic Core Scales could be successfully used to evaluate physical, emotional, social and school functioning of hospitalized children and adolescent. Schoolchildren hospitalized for prolonged tumor treatment have poorer HRQOL scores compared to general healthy population, however the level of remaining physical, emotional and social parameters should provide solid foundation for their potential rehabilitation, education and inclusion.

Key words:
quality of life; neoplasms; questionnaires; child;
adolescent.

Apstrakt

Uvod/Cilj. Iako je dužina života dece obolele od maligne bolesti značajno povećana, produženo lečenje i hospitalizacija mogu imati negativni uticaj na njihov razvoj. Cilj našeg istraživanja bio je da se utvrdi profil zdravstvenih parametara kvaliteta života populacije školske dece obolele od maligne bolesti tokom njihove hospitalizacije i lečenja. **Metode.** Primenjena je srpska verzija testa „Pediatric Quality of Life Inventory Version 4.0 (PedsQL™4.0) Generic Core Scales“. Testirano je ukupno 120 školske dece, od toga 60 hospitalizovane radi produženog lečenja maligne bolesti i 60 zdrave školske dece iz osnovnih i srednjih škola. Istraživanje je sprovedeno u Institutu za onkologiju i radiologiju Srbije i u četiri škole. **Rezultati.** Generalno, školska deca hospitalizovana radi lečenja kancera pokazala su slabije rezultate u fizičkim, emocionalnim, socijalnim i školskim parametrima u poređenju sa zdravom školskom decom iz redovnih škola. Značajne razlike uočene su u svih osam parametara na fizičkoj skali, u dva od pet parametara na emocionalnoj skali, u četiri od pet parametara na socijalnoj skali i u tri od pet parametara na školskoj skali. **Zaključak.** Srpska verzija „PedsQL™ 4.0 Generic Core Scales“ testa može biti uspešno upotrebljena za utvrđivanje fizičkih, emocionalnih, socijalnih i školskih parametara funkcionisanja hospitalizovane dece i adolescenata. Školska deca hospitalizovana radi produženog lečenja maligne bolesti pokazala su lošije rezultate pri analizi kvaliteta života od zdrave školske dece. Međutim, preostali stepen funkcionisanja na fizičkom, emocionalnom i socijalnom nivou obezbeđuje solidnu osnovu za njihovu rehabilitaciju, obrazovanje i inkluziju.

Ključne reči:
kvalitet života; neoplazme; upitnici; deca;
adolescenti.

Introduction

During the past decades, long-term survival of children and adolescents diagnosed with malignant diseases significantly improved. Yet, some evidence suggests that medical treatment results in improved health status of patients and their prolonged and frequent hospitalization during this sensitive period of life could negatively impact child development. Therefore, there is an increasing interest in the development and inclusion of measures for health-related quality of life (HRQOL) outcome in modern clinical practice¹.

The HRQOL is a multidimensional construct compiled of the patient's perception of the impact of the disease and treatment on his/her functioning in different aspects of life including physical, mental, and social domains². Pediatric HRQOL measurement instruments must in addition be sensitive to cognitive development and to include both child self-report and parent proxy-report³. Furthermore, a relatively short self-report questionnaire is essential for administration to children given their short attention spans when compared to adults. Results obtained using HRQOL measurement instrument could be used in health status tracking, evaluation of treatment outcomes, research, school health settings and community population³.

The Pediatric Quality of Life Inventory (PedsQL) is standardized assessment instrument developed by Varni et al.⁴. This instrument systematically evaluates patients' and/or parents' perception of HRQOL in pediatric patients with chronic health conditions using pediatric cancer as an exemplary model⁴. The PedsQL 4.0 Generic Core Scales were constructed to measure core physical, mental, and social health dimensions as delineated by the World Health Organization, but also to include school functioning⁵. The measurement properties, reliability and validity of the PedsQL 4.0 in pediatric cancer were demonstrated in several studies^{2, 5-12}. On the other hand, only a few studies were performed with pediatric malignant disease patients during ongoing oncological treatment and hospitalization.

HRQOL instruments are expected to be simultaneously developed across different cultures and languages in order to ensure measurement equivalence between original and new local versions. PedsQL Generic Core Scales are translated into 73 languages or dialects among which is Serbian language^{13, 14}. Recently, the Serbian version of PedsQL 4.0 Generic Core Scales self-report version for children and adolescents has been evaluated¹⁴. The study confirmed appropriate internal consistency reliability of the scales that is sufficient for group evaluations, and good convergent validity against psychological constructs. However, the Serbian PedsQL was validated and tested only on general healthy population of children.

The aim of our study was to determine the profile of HRQOL parameters in population of schoolchildren diagnosed with malignant diseases during the first year of the treatment and hospitalization. Based on the previous reports cited above, we hypothesized that children and adolescents hospitalized for malignant disease treatment would demonstrate lower HRQOL scores compared to general population.

Since all the tested patients were enrolled to special hospital school service during hospitalization, and due to the fact that their parents were present for most of the hospitalization time, we expected to identify a significant level of preserved psychosocial functions.

Methods

The study comprised a total of 120 schoolchildren, aged 8–18 years and equally boys and girls from Serbia. Out of 120 children and adolescents 60 were patients recruited from the Institute for Oncology and Radiology of Serbia (IORS). The patients were considered eligible if they were: 8–18 years old, diagnosed with malignant disease confirmed with histopathological examination, without comorbid disease or major developmental disorders, receiving treatment and hospitalized in the Department of Pediatrics at the IORS. The patients were excluded if they were not clinically stable or not cognitively able to complete the questionnaire. All the patients from the IORS were enrolled to hospital school service according to their age and previous grade they attended in regular school. Another group of 60 healthy schoolchildren of the same age and sex were chosen as control from two primary and one secondary public schools.

All the children and adolescents, as well as their parents, were informed about the purpose of the examination and they gave consent. Child-report questionnaires were self- or interviewer-administered to participants.

The study was approved by the Ethical Committee of the IORS (study approval No 1005/1-01) and from Institutional Review Board of IORS.

To assess health-related quality of life factors in both, patients and healthy schoolchildren, the PedsQLTM 4.0 Generic Core Scales¹³ were applied. The 23-items of this scale encompass: Physical Functioning Scale (8 items), Emotional Functioning Scale (5 items), Social Functioning Scale (5 items), and School Functioning Scale (5 items).

The scales ask about the frequency of a problem of each item within the past month. All items are in a 5-point response scale (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reversely scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better health-related quality of life parameters. Scale scores are computed as the sum of the items divided by the number of items answered. If more than 50% of the items in the scale were missing, the Scale Score was not calculated.

The Serbian version of PedsQLTM 4.0 was provided by the MAPI Research Trust and permission was obtained from the author, Prof James W. Varni¹³. Serbian PedsQLTM 4.0 is feasible, short and easily scored questionnaire for health-related quality of life assessments in children and adolescents. The Serbian version of PedsQLTM 4.0 has appropriate internal consistency reliability as confirmed in the previous report¹⁴.

To describe parameters from PedsQLTM 4.0 scales we calculated mean values, standard deviations (SD), frequen-

cies and range values. As statistical instruments, we used Kolmogorov-Mirnov test (K-S test), Histogram, Scatterplot and QQ Plot. To test the difference between parameters we used Welch Two Sample *t*-test, Fisher Exact Test and Pearson χ^2 test.

A statistical significance in correlations was only accepted at $p < 0.05$.

All the tests were performed using free statistical package "R Project for Statistical Computing" (version 2.6.0).

Results

This research enrolled a total of 120 schoolchildren during the years 2006, 2007 and 2008. A descriptive infor-

mation services synchronized with regular school programs they were enrolled prior to hospitalization.

The sample of patients was heterogeneous with respect to tumor pathology (solid tumors and malignant hemopathies), disease stadium (localized and disseminated tumors) and duration of the disease (median time from diagnosis was 2.6 months). All the patients were subjected to the malignant disease treatment. Thirty seven patients (61.67%) went under chemotherapy treatment, two patients (3.33%) radiation treatment, and twenty one patients (35%) a combined therapy. In 8 cases malignant disease was previously diagnosed in one or more members of the family (13.33%) (Table 1).

Table 1

Demographic and clinical characteristics of the sampled children		
Characteristic	Healthy n (%)	Patients n (%)
Gender		
total	60 (50.0)	60 (50.0)
female	30 (50.0)	30 (50.0)
male	30 (50.0)	30 (50.0)
Age, years		
average (mean \pm SD)	13.22 \pm 3.15	12.98 \pm 3.05
8–12	30 (50.0)	30 (50.0)
13–18	30 (50.0)	30 (50.0)
School enrollment		
primary school	41 (68.33)	41 (68.33)
secondary school	19 (31.67)	19 (31.67)
Medical diagnosis		
solid tumor		43 (71.67)
malignant hemopathy		17 (28.33)
Disease stadium		
localized		21 (35.0)
disseminated		39 (65.0)
Duration of the disease, years		
average (mean \pm SD)		2.6 \pm 1.08
up to 1 month		12 (20.0)
1–2 months		15 (25.0)
3–6 months		18 (30.0)
more than 6 months		15 (25.0)
Treatment received		
chemotherapy		37 (61.67)
radiation		2 (3.33)
combined therapy		21 (35.0)
Family history of cancer		
no		52 (86.67)
yes		8 (13.33)

SD – standard deviation

mation about the sample is presented in Table 1. For both healthy and patient group, equal number of 60 participants was selected with equal proportion of boys and girls (50 : 50). Children were selected to represent a complete range of years from 8 to 18 (Table 1 and data not presented) with equal age distribution. The median age of the children from the healthy group was 13.22 years, and median age for the patient group was 12.98 years, showing statistically non-significant difference. Children from both groups were enrolled in a primary school (68.33%) or secondary one (31.67%). Healthy schoolchildren were chosen from regular public schools, and the patients were receiving special edu-

A total of 120 questionnaires on child self-report were analyzed for HRQOL scores. Items on which less than 50% of respondents gave clear and definitive answer were not calculated for the statistics. Mean values for items from PedsQL Generic Core Scales are presented with SD for both groups in Table 2. In order to determine differences in HRQOL scores between the healthy schoolchildren group and the group of schoolchildren hospitalized for cancer treatment the *t*-test was conducted.

Comparisons with the reference healthy group show that a entire patient sample has a lower health-related quality of life values in several domains. Significant differences

Table 2
Scale descriptives for PedsQL Generic Core Scales Child Self-Report and comparisons with Healthy Children Scores

Scale	Healthy mean \pm SD	Patients mean \pm SD
Physical health		
It is hard for me to walk more than one block	81.25* \pm 22.84	52.5* \pm 35.86
It is hard for me to run	79.17* \pm 25.7	39.58* \pm 32.96
It is hard for me to do sports activity or exercise	80.83* \pm 23.64	42.08* \pm 34.29
It is hard for me to lift something heavy	68.75* \pm 28.97	44.17* \pm 31.68
It is hard for me to take a bath or shower by myself	85.42* \pm 26.56	69.58* \pm 32.58
It is hard for me to do chores around the house	70.83* \pm 28.06	53.75* \pm 32.16
I hurt or ache	81.67* \pm 23.41	72.08* \pm 25.25
I have low energy	78.75* \pm 25.97	67.5* \pm 24.05
Emotional functioning		
I feel afraid or scared	68.33 \pm 19.46	63.75 \pm 25.39
I feel sad or blue	65 \pm 22.64	58.75 \pm 24.28
I feel angry	70.83* \pm 22.15	59.17* \pm 24.77
I have troubled sleeping	76.25 \pm 23.66	72.92 \pm 23.6
I worry about what will happen to me	66.25* \pm 30.82	55* \pm 28.3
Social functioning		
I have trouble getting along with other kids	90.83* \pm 17.81	79.58* \pm 25.83
Other kids do not want to be my friends	82.5 \pm 21.74	80 \pm 27.15
Other kids tease me	85* \pm 23.11	52.5* \pm 30.08
I cannot do things that other kids my age can do	89.58* \pm 24.48	67.08* \pm 33.03
It is hard to keep up when I play with other kids	78.75* \pm 25.14	63.33* \pm 29.28
School functioning		
It is hard to pay attention in class	76.25* \pm 32.03	55.83* \pm 31.68
I forget things	67.08* \pm 30.07	43.33* \pm 25.98
I have trouble keeping up with my schoolwork	70* \pm 31.82	35.42* \pm 36.04

*Result shows statistical significance – $p < 0.05$

between healthy schoolchildren and patients hospitalized for treatment were observed for all 8 items of the Physical Health Scale. The children from the healthy group showed the expected mean values, while the patients demonstrated significantly lower mean values ($p < 0.05$). Schoolchildren on treatment for cancer demonstrated lower scores on all the items of the Emotional Functioning Scale, although a statistically significant difference was detected only for 2 items. Healthy schoolchildren revealed expected median values in all the items of the Social Functioning Scale, while the patients showed lower scores in all the items and a statistically significant difference in 4 out of 5 items. Lower mean values for the patients were also observed in the School Functioning Scale for 3 items, showing a significant difference.

Discussion

The PedsQL™ 4.0 Generic Core Scales designed for application in both healthy and patient populations^{3, 15, 16} is one of the most used instruments of HRQOL measurement. The reliability and validity of the PedsQL™ 4.0 Scale was previously demonstrated, confirming that the Scale may be utilized as an outcome measure in clinical trials, research and clinical practice⁵. Recently, some psychometrics properties for the Serbian child self-report version of PedsQL were reported. Shortly, authors¹⁴ demonstrated that the Serbian version of PedsQL 4.0 has sufficient basic measurement characteristics, adequate overall internal consistency reliability sufficient for the group evaluations and good convergent validity against psychological construct. Although, authors re-

ported that alpha value did not exceed 0.70 for the School (0.65) and Emotional Functioning (0.69) this level is appropriate for comparing the groups¹⁴.

We assessed HRQOL scores of schoolchildren diagnosed with malignant disease and hospitalized for treatment, and compared them to healthy schoolchildren population. In general, we detected a negative impact of malignancies on HRQOL parameters tested with PedsQL scales. We found a statistically significant difference in all the parameters of Physical Health Functioning were found: walking, running, exercising, lifting, bathing, cleaning, pain and low energy. The mean values for physical parameters are comparable to the results published in the similar previous studies^{5, 11, 12, 14}. As expected, the obtained results demonstrate that malignancy and prolonged hospitalization of patients were accompanied by difficulties in activities of daily living and impoverished quality of life.

The mean values for five parameters of the Emotional Scales for healthy population were lower when compared to those obtained in some other reports^{5, 17}, but similar to those reported in a recent study on Serbian general population¹⁴. This might be due to the fact that alpha value for the Serbian version of PedsQL did not exceed 0.70 for the Emotional Functioning Scale (0.69). Still, this level should be appropriate for comparing the groups, but not for individual patient scale scores. Only two out of five parameters showed a significant difference in hospitalized schoolchildren when compared to healthy schoolchildren. A statistically significant difference was not detected in all items probably due to hospitalization of patients in the institution with the special child care unit, spe-

cial education service, supportive programs and constant presence of their parents. We believe that comparable Emotional Functioning Scale scores for patients and healthy schoolchildren might be the consequence of this practice.

Social functioning was strongly affected in schoolchildren hospitalized for malignant disease treatment. The mean values for all five parameters of the Social Functioning Scale are comparable to those obtained in similar studies^{5, 7, 11, 12}. The mean values were decreased in patients compared to healthy schoolchildren population, and four out of five parameters showed statistically significant differences. Obviously, children with malignancies felt and reported difficulties in making friends and keeping pace with other children.

As expected, malignant disease and prolonged hospitalization due to the treatment strongly affected school functioning parameters like attention, memorizing the facts and schoolwork. These parameters also demonstrated a statistically significant difference when compared to the schoolchildren from the healthy group.

Conclusion

Our results revealed that the Serbian version of PedsQL™ 4.0 Generic Core Scales could be successfully used to evaluate physical, emotional, social and school functioning of children and adolescents. Schoolchildren hospitalized for prolonged tumor treatment have poorer HRQOL scores compared to general healthy population, as expected. On the other hand, the level of remaining physical, emotional and social parameters in schoolchildren hospitalized for prolonged treatment should provide solid foundation for their potential rehabilitation, education and inclusion. Further testing should be done on this population after they finish hospital treatment to determine achievement of process of rehabilitation. We believe that child self-reports of HRQOL parameters using PedsQL Scales regardless some imperfections might be important tool in future determination of programs for rehabilitation and education of hospitalized schoolchildren.

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